# VOICE OF THE DIABETIC

A SUPPORT AND INFORMATION NETWORK

*The Diabetic Division of The National Federation of the Blind*

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## This Issue Will Include:


Blindisms of Professionals by Dr. C. Edwin Vaughan ..... 1
My Pancreas Transplant — The Impossible Dream by John Redlin ..... 2
I Lost my Pancreas by John Redlin ..... 3
Results of Pancreas Transplants at the University of Minnesota Hospital by Ed Bryant ..... 3
Ask Dr. James by Dr. Ronald James, M.D. .... 4
By Striving Together We Can Change Things by Ed Bryant ..... 5
Letter To The Editor by Cecilia Shannon ..... 6
Modifications on Insulin Techniques for the Visually Impaired or Blind Diabetic by Alice Raftary, B.S., M.Ed. . 6
Recipe Corner ..... 9
Meat Exchange List by Diabetes Treatment and Education Center ..... 9
What You Always Wanted to Know But Didn't Know Where to Ask (Resource List) ..... 11
Tidbits and Humor ..... 12
A Sermon Without Words ..... 12


## Blindisms of Professionals


by Dr. C. Edwin Vaughan
Professor, Department of Sociology,
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*Dr. Ed Vaughan has a long history of advocacy and does everything possible to eradicate discrimination and misunderstanding about blindness. He serves as Professor of Sociology and Director of the Center for the Study of Aging at the University of Missouri-Columbia. He is also a local activist and a strong supporter and member of our organization, the National Federation of the Blind.*

While working with both public and private agencies serving the blind, I have frequently observed the behavior of workers representing such agencies. Being a sociologist, I am interested in the studied friendliness of front line and administrative workers and how quickly rapport fades away when their decisions or procedures are questioned by the consumer. Happily, this is not always the case. There are many individuals whose behavior demonstrates openness and a willingness to treat the opinions of the blind consumer with consideration and respect.

Why the defensiveness? Why not openness? Why not appreciation for the questioning individual who is seeking greater control over his or her life? Why not pride in the contribution some agencies and some workers have made to the rehabilitation and increasing independence of many blind individuals?

Most who study the philosophy and history of the National Federation of the Blind cannot help being impressed by the contribution this organization has made to the lives of its members and all blind people. Yet, today we have a polarized situation where many agencies and national organizations decry the NFB as being made up of trouble makers and uninformed, ill-intended individuals. Even if agency personnel don't always agree with or like the strategy and tactics of the National Federation of the Blind, why not yet be supportive of an organization which pays its own way, has brought itself up by its "boot straps", is seeking self-direction and autonomy for its members and all blind people? Hopefully, this autonomy and self-direction is still a major goal for any rehabilitation effort.

I think the answer lies in the vested interests frequently being protected by the personnel of agencies and organized service delivery settings. Although certainly not as large as international corporations or the Fortune Top 500, the rehabilitation business has been a steady growth industry with relatively good salaries, long term careers, and good retirements to be had. This industry is always located in a large organization or bureaucracy, which provides the mechanisms and network of social relationships to assure the stability and control of the organization. Control comes from the top down.

Although some caregivers are sensitive to the consumer's frustration with the dehumanizing aspects of bureaucratically organized service delivery, the organizational pressures to work within the established structure and tradition are enormous. If one identifies too closely with clients and attempts to minimize the consequences of the organizational processing of people, they will eventually have to challenge the agency structure and its rationale — an action that involves considerable personal risks. From the agency perspective the inability to distance oneself from the particularistic considerations of clients is an indication of a lack of professionalism which lessens the agency's overall effort to provide services to clients in the most efficient, rational manner. Defensive behavior is one way of avoiding pressures for change coming from increasingly informed consumers.

Another major source of the defensive behavior we are describing resides in the dynamics by which organizations establish and maintain legitimacy. In order to be legitimated as appropriate care providing organizations, client centered agencies present their personnel as providing services based on professional expertise that is not shared by the general public or clients. On the one hand, they use these claims of specialized knowledge and technologies to obtain external resources from the agency; claims of professional expertise are also utilized in the administration of service programs and in the management of clients. But professional claims and their implementation have important and far reaching implications for the nature of the relationship between care providers and clients.

Briefly stated, the notion of professionalism in this context implies that there is a body of knowledge relevant to delivery services to the blind that has been mastered by the limited number of specialized practitioners in the field. Decisions as to appropriate services for blind clients are said to be based on principles anchored in and deriving from this specialized body of knowledge and skills. As a result of competent mastery of these principles, the professional claims an exclusive privilege to decision making in the specialized setting. When he or she disagrees, the client as a nonprofessional is deemed unqualified to participate

(Continued on page 4.)


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# My Pancreas Transplant — The Impossible Dream

by John Redlin

*This issue's three articles concerning pancreas transplantation are quite lengthy. However, all diabetics are inspired by the possibility of a cure being found for diabetes. So, after due consideration, it was decided that this subject, which touches the lives of many newsletter readers, merited much attention.*

*The following has been taken from a presentation John made to his fellow congregation members at the Lutheran Memorial Church, in Fort Pierre, S.D., on Palm Sunday, 1985.*

I'll tell you a story that is unfortunately neither unique nor unusual. On June 15, 1958, God gave me a cross to bear: a disease called diabetes. I had little idea then how heavy that cross would become. Doctors only told me I was condemned to a life of taking daily injections, and following a restricted diet. At the time things didn't seem too difficult to adjust to, but there was also the prospect of living with an incurable disease I'd never outgrow. At that moment I didn't know how heavy that cross would become. I would learn only too soon.

The doctors had warned me that diabetes was full of valleys and low spots. It has lots of mountains to climb and some very crooked paths to follow and there were bound to be some rough places along the way. Early on, I found a verse from Isaiah that became very meaningful for me. It became a mainstay verse for my spirit. Isaiah says, "Every valley shall be exalted and the mountains and hills be made low, Crooked places shall be made straight, and the rough places shall be made plain."

By 1975, I became aware of how heavy the burden would become. By them, I'd observed some very subtle changes from my diabetes. Initially my eyes were affected; I began losing my vision.

One day in school, a flash of red went across my eyes as I yelled at a student in the classroom. I checked with the doctors and was immediately sent to Minneapolis, where I received "laser treatments." Those saved the little vision I had left.

By June 1976, I'd lost all vision in my right eye, and the reading vision in my left. I felt devastated because reading was so important in my life. When I arrived home, my parents urged me to rest and relax. They brought me to the garden to do a little work, something we loved to do together. My mother said, "John, why don't you pull out those weeds from that row of beans?" Any good gardener knows that beans are the most identifiable garden crop. But when I finished my work and stood back to look at the 30-foot row, I saw I'd pulled out all the beans, instead of the weeds. It was then I realized how serious my condition was. I sat down at the row's end and cried like a baby. I sobbed "God, why are you punishing me? Why are you doing this? What have I ever done to deserve this?" At that moment, I felt like Job must have felt when his whole world came crashing down around him.

**"Throughout my life, I've relied on what I call my 'three F's' — faith, family and friends."**

By August 1, 1976, my world was crashing down around me. During a clinic visit, my doctors warned that my condition had become critical. If I didn't return home and find a kidney donor, I could count on living only six months longer. Throughout my life, I've relied on what I call my "three F's" — faith, family and friends. I prayed to God, saying, "God please! don't let me die. I'm not ready, I have too many things left to do." I returned home and asked my family about a kidney donor. Each of my six brothers and sisters volunteered and said, "take me." But a battery of clinical tests determined my brother Jim as the best choice. In January, 1977, I received Jim's kidney in a transplant operation. Jim gave me "The Gift of Life." Three weeks after the operation, I left the hospital. Within two months, I was back at work, substitute teaching. I felt marvelous.

The next six years sped by. But again, I started noticing more changes in my condition. Diabetes was inducing subtle changes in my vision, and my legs weren't as strong as they'd been. Also, I was beginning to worry about the kidney Jim had given me, that somewhere in the future, it too would be affected by diabetes and fail, just as my own had failed earlier.

But doctors came and offered new hope: the possibility of a pancreas transplant. I said I was willing to handle all the risks. They said they could offer the chance immediately. "We've only done a few," they admitted, "but it's a chance that we could cure your diabetes." I told them that I was definitely interested. They asked me to do two things before the operation: 1) to return and discuss it with my family to see whether any of them were willing to donate; 2) to look for a good insurance policy or $40,000 to pay for the operation.

When I went home and approached my family, again, all six brothers and sisters wanted to be the chosen donor. But the tests again pointed to Jim as the best choice. I returned to Fort Pierre and called my own insurance company; they refused to handle it. "It's just too experimental," they replied. Another mountain, another valley.

I prayed for an answer, which came through my third "F", "Friends." Two particular friends, Ed and Joe Cummings, helped me out. Ed was a fellow member of the Lions Club; Joe taught school with me. We went out to dinner. Ed asked, "John, if you had the money would you have a transplant?" I answered, "Well, we're talking $40,000." He said, "That's not what I asked you. I said, if you had the money, would you have the operation?" I answered, "Of course"; Ed said, "So we'll get it." He continued, "John, all we've got to do is locate 400 people to donate $100.00 apiece and we've got it made." I thought, "Boy, with an attitude like that, I'd have been willing to try anything."

So in November, they organized "John Redlin Day." People came from all around to help raise money for me in the name of diabetes and diabetic research. In one day, they collected more than $36,000. The Lions Club, Aid Association for Lutheran Brotherhood, and teachers from around the state participated. People at Lutheran Memorial even ate Lutefiske to contribute to the cause. All the money came in, and the date was set for January 29, 1985, with brother Jim as the pancreas donor.

Some years ago, during the late '60s or early '70s, a Russian cosmonaut in his spacecraft circled the earth for several days. When he returned to earth, he proudly announced, "I've been in space and I didn't find God." There were many intellectuals running around the world claiming "God is dead." But I have news for them, God is not dead, he is alive and well, and doing a fine job. I offer the following evidence.

On January 28, the night before my operation (scheduled for 6 a.m.), my parents had come to visit, then gone home to rest. Pastor Dennis Trandberg came to visit. He read the 27th Psalm to me. We talked and he gave me communion. I felt I was all ready to go. At 9:30 p.m., my brother Jim walked into my room with my parents. My dad announced, "John, Jim wants to say something."

Jim stood beside my bed. Suddenly he broke down and began sobbing. He cried, "John, I can't do it. I just can't do it, they didn't tell me everything I needed to know, and there are complications I can't risk with Marla and Jenny" (wife and daughter). He cried, "There's too much at stake."

I grabbed Jim and hugged him. I said, "Jim, let's not worry about it; this is no life and death situation. But anyway, God will provide." I reminded him that he'd already saved my life once — 8 years ago. A few minutes later, the phone rang. Dr. Sutherland, head of the Pancreas Surgery Department, called to tell me about his conversation with Jim; he knew Jim had reconsidered.

Then he said he had good news. He wanted to tell me there was a cadaver pancreas available. I hung up the phone and continued talking with Jim.

My mother asked, "John, do you remember Ken Muir? Ken Muir was one of two FBI agents who was gunned down in North Dakota two years ago by Gordon Koll and members of the Posse Comitatas. Now Ken Muir was also the uncle of my brother-in-law, Jim Kendall," my mother reminisced. "You know," she said, "here we are getting so wrapped up in our own problems, we've failed to look at the problems of others. Think of that poor family, not only losing him, but three nights ago, Ken's little grandson was killed in a car accident in Fargo." As we were talking about the tragedy that that family had to suffer, the phone rang. It was Dr. Sutherland.

**"... I want it to succeed in honor of that little boy who's no longer there for his parents and family, but who lives on in five other people."**

Now, I'm a little bit selfish. I wanted the best possible chance of success in this operation. So I had one question I needed to ask him, "Doctor tell me, what's the condition of the donor?" He said,

**(Continued on page 10.)**

# I Lost My Pancreas

by John Redlin

My pancreas transplant succeeded for nine months. The graft had to be removed in October, 1985, because I developed an abdominal abscess. The abscess was caused by an unrelated condition. It was one of Dr. Sutherland's most difficult medical decisions. Up until the time that I went to surgery, the pancreas worked perfectly. My blood sugars never went over 100 and remained constantly between 80 and 100 — something I'd never dreamed possible.

The pancreas had to be removed because the abdominal abscess perforated my small intestine. The doctors didn't know what caused the perforation, but it developed into an abscess situated in such a way that made it life threatening to me. They decided to remove it.

During the nine months I lived free from insulin, I led a life I'd never dreamed possible. Life was not only free from shots, but also from worry about insulin reactions, the thing that had plagued me most in the last 5 to 10 years. My life was unrestricted. I did things I never believed possible. I ate when I wanted to eat — not on any schedule. I was totally free of the restricted life style my diabetes had imposed on me. I was like a liberated slave. No one, except another diabetic, could appreciate that type of freedom.

I hated to lose that pancreas graft for many reasons. I hated to lose the direct connection with the family. When I had the pancreas removed, I felt like another part of my young donor had died inside me. I hated to lose it because it meant returning to insulin and leaving the life of freedom I had led for nine months. It was tough to sacrifice all that, but now the doctors are encouraging me to have the operation again.

I'm putting my name on the waiting list for cadaver transplants in May, 1986, in the hope that this summer I will have another transplant.

I receive many questions about pancreas transplantation and I'd like to answer some:

1) Where can I have this done? I recommend people go to the University of Minnesota in Minneapolis. These doctors are pioneers in the operation. They're the ones most experienced in the procedures. They're the ones who can offer the greatest chance of success.

2) What are the chances for success? The chances for success depend on whether you have a live donor or a cadaver. If people are fortunate enough to have a living relative donor, the chances for success are better than for those with a cadaver, but nothing is definite. Statistically speaking, the living relatives success rate is between 70-80%. The cadaver success rate is between 25-50%. They have done very few transplants at this point. I was only number 106 when I had mine in January, 1985.

*(Editor's Note: The University of Minnesota has now done over 130 pancreas transplants.)*

3) What happens during the operation and is it risky? The operation is major surgery. You will probably be admitted to the hospital for a preliminary operation called a "Rue-N-Y." This means they remove part of the bowel and cut the small intestine to leave a place for the new pancreas. They let you heal for a month or two and then do the pancreas transplant itself.

4) What is post-op like? Recovery time after the transplant is around 14 days. I left the hospital after 14 days; at that point my diabetes was cured. I was back at work in 5 weeks. I felt fine. There are restrictions on your activity, as there are with any major surgery. There are always potential complications. The more one worries about complications, the lower are the chances of success. Having a positive attitude in an operation like this is critical. You must have a positive attitude any time you have surgery. After the surgery, one takes immunosuppressant drugs. These may be prednisone, imuran and/or cyclosporin. All these are commonly prescribed after the operation to prevent rejection.

**(Continued on page 10.)**

# Results of Pancreas Transplants at the University of Minnesota Hospital

by Ed Bryant

In trying for a complete "cure" for diabetes, the Minnesota transplant team at the University of Minnesota Hospital in Minneapolis, Minnesota has sparked renewed interest in the possibility of pancreas transplantation. Dr. David E.R. Sutherland heads the pancreas transplant team and has detailed a truly pioneering effort which now attains a 27 percent one-year functioning graft-survival rate.

The surgery team has learned much from the results of their work, including the documentation of recurrent diabetes in recipients of isografted pancreases. An analysis of the results of the pancreas transplants is given in an article by Dr. Sutherland and his colleagues. According to the article, there is suggestion of "a favorable effect on secondary complications," but the transplant team believes that "pancreas transplants need to be performed much earlier than has been generally advocated."

Between December, 1966 and September, 1984, 114 pancreas transplants were performed in two series at the University of Minnesota. The second series, begun in July, 1978, included 100 pancreas transplants in 86 patients and encompassed several alterations in surgical technique, graft preservation, recipient immunosuppression and recipient and donor selection. These changes were made as an attempt to produce a method that would result in a high success rate.

Donor pancreases were procured from both cadavers and living relations. Initially, pancreas transplants were performed only in patients with previous kidney transplants. In recent years, however, most recipients have been nonuremic, non-kidney transplant patients with early or only moderately advanced but not progressive secondary complications.

The article states that from July 25, 1978 to September 14, 1984, there were 100 pancreas transplants performed in 86 diabetic patients. At the time of primary pancreas transplantation, the patients (33 male, 53 female) ranged in age from 16 to 52 years. Duration of diabetes at the time of pancreas transplantation ranged from 10 to 40 years. Of the 100 grafts, all but 3 functioned immediately; 28 failed for technical reasons. There were 86 recipients of technically successful pancreas allografts.

As of November, 1984, 70 of the 86 recipients were alive and 28 had functioning grafts of which 22 were insulin-independent, 14 for more than one year. In the entire series, graft losses have been attributed to technical causes in 28 instances, to probable rejection in 39 cases and to recurrence of disease in 3 patients. Five persons died with functioning grafts. For all cases, one-year actuarial patient and graft survival rates were 86 percent and 27 percent, respectively. The survival rate has been significantly higher for recipients of grafts from related than from cadaver donors (95 percent vs. 76 percent at one year).

Pancreas transplants have usually been performed in diabetic patients with far advanced complications, most of whom have had end-stage diabetic nephropathy treated with a kidney transplant either before or after the pancreas transplant. The exact benefit imparted to renal allograft recipients by a pancreas transplant is uncertain, but since these patients already receive immunosuppression to prevent rejection of a kidney, a pancreas transplant entails, as an added uncertainty, only the surgical risk. A solid case can be made for its application, however, because a successful pancreas transplant may protect against recurrence of disease in the transplanted kidney.

The surgical team has experimented with different immunosuppressive protocols and their findings are documented in detail for the benefit of people interested in pancreas transplants.

We, the diabetics, eagerly await additional advice from Dr. Sutherland et. al. as to when and in which diabetic a pancreas transplant may prove beneficial.

**Source:** Sutherland, David E.R., M.D., Ph.D., et al. "Effect of Multiple Variables on Outcome in Pancreas Transplant Recipients at the University of Minnesota and Preliminary Observations on the Course of Preexisting Secondary Complications of Diabetes." Diabetic Renal-Retinal Syndrome 3, 1986, pp. 481-497.

## Ask Dr. James

by Ronald C. James, M.D.

*Please note: If you have any questions for Dr. James please send them to the editor. The only questions Dr. James will be able to answer are the ones used in his column.*

*Question from the Editor: I would like to know, if one of our readers sends in a question that you can't answer, will that entitle me to a free office visit?*

*The answer is no. I will double the fee for that visit.*

*Question 1: Could you please explain the difference between hypoglycemia and sugar diabetes and how do the symptoms differ?*

Hypoglycemia simply means low blood sugar and has many different causes. Sugar diabetes is a condition in which many chemical abnormalities occur, an elevated blood glucose usually being one of these abnormalities. It results either from an abnormal (usually decreased) production of insulin or inadequate response to the insulin which is produced. In fact in some cases hypoglycemia may be a symptom of Type II (non-insulin dependent) Diabetes. This occurs when there is a delay in the production of insulin following the ingestion of food. In such cases the food is utilized before the insulin is produced. Then at the time of insulin production there is little food available and, as expected, one may develop hypoglycemia.

The symptoms of diabetes and hypoglycemia generally differ in most cases. With hypoglycemia they are many and varied. Basically they result from two mechanisms. One is that the brain does not function properly when the blood glucose is low. Under such circumstances anything may occur that can go wrong when the brain does not work properly. This may include strange behavior, confusion, difficulty with speaking, difficulty walking, hunger, and even blackouts and convulsions. The second mechanism is due to the adrenalin that is produced in response to the low blood glucose. It may make one shaky, make his heart beat rapidly, dilate his pupils causing blurred vision, and cause him to sweat profusely.

The symptoms of diabetes are generally considered to be those of hypoglycemia and diabetic ketoacidosis. These include increased thirst, increased urination and possible weight loss. Nausea, vomiting, and dehydration may occur under extremely severe conditions.

Such a person will appear to be ill and may be short of breath because of the increased acid level that occurs.

*Question 2: What suggestions would you give to the diabetic traveling away from home on vacation? I am concerned about insulin storage, food and meal planning.*

My best advice is to be prepared. With respect to insulin and its storage I would suggest that one take a double supply of insulin when traveling because if he would happen to break or lose a bottle of insulin it might be difficult to rapidly replace it in an unfamiliar location. The insulin should not be stored where it will be frozen or where it will become extremely hot. In hot weather it can be kept either in a cooler or in a large-mouth thermos bottle containing a few ice chips. When traveling by airplane always keep the insulin in the cabin with you.

If the diabetic knows his meal plan generally he can eat out and do fairly well. He may not be able to get all of the foods he needs and therefore will need to supplement those he can purchase to complete the meal plan. Therefore it is wise to take some food along. If traveling by automobile it can be kept in a cooler. It is also important to carry some extra food when traveling by airplane because they often will not meet planned schedules and may not have appropriate food on the plane. One can take crackers, dried fruits, powdered milk, canned meats such as sardines, oysters, or vienna sausage, dried meats, canned juices, etc. Raw, unprocessed foods may not be permitted.

Again, the words are BE PREPARED.

*Question 3: What is the glucose tolerance factor and does it help diabetes?*

The "glucose tolerance factor" is a molecular complex made up of a combination of nicotinic acid and chromium. Current scientific evidence has not yet established that chromium deficiency is a cause of diabetes or that supplementation with chromium or the "glucose tolerance factor" is in any way beneficial in the treatment of most diabetics.

Some studies suggest that chromium deficiency may lead to impairment of glucose tolerance in some older individuals but no definite relationship between chromium deficiency and diabetes has been established for most individuals.

*Question 4: What do you think about diabetics taking extra supplements which are supposed to be good for their diabetes? I'm specifically referring to chromium, vitamin E, magnesium and the B-complex vitamins.*

Briefly, I don't think much of the use of supplements for diabetes. There is no evidence that these substances have anything to do with diabetes or its chronic complications.

*Question 5: Is diabetes inherited or how does one catch it?*

First, one does not catch diabetes. As far as we know it is not the result of an infectious agent although in certain cases an infection may possibly precipitate an auto-immune process that could result in the development of Type I Diabetes. The exact mode of inheritance of diabetes is not well worked out. Nevertheless there is no doubt that it runs in families. One factor making it difficult to understand and determine the genetics of diabetes is that it is probably a group of many different diseases that have in common hypoglycemia but which have different modes of inheritance.

## Blindisms of Professionals

**(Continued from page 1.)**

in actual decisions or to pass judgement on these decisions and their implementation. It is the personnel of these agencies who develop statements of clients' needs and how these needs are to be properly attended. Too often agency personnel define the meanings of and responses to blindness for clients, rather than assisting clients in dealing with their own conceptions of blindness.

Agency personnel not only legitimate their decisions on the basis of professional norms and procedures, they implement these decisions within a system of relations that further structures the caregiver-client relationship in favor of professional interests. Because the agency controls the needed rehabilitation service resources, the relationship is one of superordinate and subordinate positions, in a relation of differential power and greater dependency. Ideally, of course, the goal of such agencies for the blind is to assist clients in their capacity to perform independently. But the very structure of the relation mitigates against the development of independence. Inasmuch as professional decisions emanate from above, this contradicts the ideal of assisting blind persons in making decisions and in taking actions that lead to self direction. Rather than producing greater capacity for independent activity, the structure of the relationship orients caregivers to the maintenance of dependency.

Organizations are created and maintained because of their presumed efficiency. Professionals are supported and recognized because of their claim to specialized knowledge. Either can result in goal displacement, that is, forgetting the original purpose. When organizations and professionals are combined the danger of goal displacement is even greater.

An activity or behavior which diminishes our dignity as humans — our uniqueness, our pride, our sense of worth and self-respect, and our ability to control our own destiny has no place in rehabilitation efforts. The customer is not always right, but in every instance he or she should be listened to with respect. Communication is difficult enough without defensive, closed behavior demonstrated by some of those who claim to serve the blind. Things will look better when the blindism of defensiveness is gone.

***Editor's Note:** The person blind due to diabetes faces the same problems as those blind due to other causes. He/she experiences much discrimination in the form of misunderstanding, presumption and myth about blind people.*

# By Striving Together, We Can Change Things

by Ed Bryant

*FRIENDS: After reading the following appeal letter, if you would like to donate to our organization, your donation will be credited to the Diabetic Division of the National Federation of the Blind (NFB).*

*As a division, we must finance our own activities. Your donation will help us fulfill this responsibility.*

*TO FEDERATIONISTS: You're welcome to use this appeal letter in whole or in part to pursue new associate memberships. Please feel free to sign your name and change the letter as you see fit. The most important thing is reaching out to others. You will be pleasantly surprised.*

*I urge you to enclose the following three items: a brochure, an associate membership form and a self-addressed envelope so that the person's response will return directly to you.*

*One federationist mailed these letters out and followed them up with calls four or five days later to make sure the letter was clear. He also checked to see if anyone needed more information and/or had decided to join.*

*Keep the calls low-key but show a genuine, gentle interest. That might help the person make a positive choice. If he or she refuses, however, we might learn how to be more effective next time.*

*Americans will donate more than 75 milllion dollars to charity this year. We only want to receive our fair share. We provide a way for our friends and neighbors to offer a "hand up" instead of a "handout."*

Today more than 12 million Americans have sugar diabetes. Diabetes is the leading cause of new blindness. There are more than 500,000 blind or visually impaired Americans. The major mission of the National Federation of the Blind is to serve all blind people regardless of the cause of their blindness.

We all have goals we endeavor to reach. We long to be productive at home, in school and in society. Some people, however, get discouraged from the start, and never get into the competition. That happens to many blind people.

Consider the following examples: A blind mother was refused a second-floor apartment because the landlord believed her blindness would prevent her from climbing the stairs.

The children of a second blind mother were taken away while she was at work because a social worker did not believe she could raise the children safely.

A blind father was denied life insurance for his infant son because of the father's blindness. One blind woman could not buy life insurance at the normal rate but had to pay a 40 percent increase in premiums because she was blind.

Another blind father seeking to buy life insurance was given $8,000 coverage after paying the price of a $10,000 policy. Finally, a blind teacher was refused a job by the school board because of her blindness.

All these situations have negative results. They assume the inability of the blind person, denying him or her the chance to disprove the initial assumption.

The National Federation of the Blind (NFB) has assisted each member discussed here. Several of these people have already won their cases. The cases pertaining to insurance and teaching are currently getting our attention. We remain optimistic about winning them all, but it will take a lot of effort by many people.

Meanwhile, we strive for consideration on the basis of our ability, not on the basis of misunderstanding, presumption, or myth. It is untrue, for instance, that blind people are automatically unhealthy or that they are expected to live shorter lives.

Blind people actually have a greater life-expectancy than sighted people.

The blind raise children and teach in public and private schools. There is also no deterrent to prevent blind people from living anywhere in a house, in an apartment or even in a tree house.

Blind people do many positive things. They're competitively employed in numerous jobs ranging from clerical to managerial positions with several hundred employees.

Teaching, parenting, studying, working, voting — blind people do all things that others do. Yet the negative instances mentioned above make all of us who just "happen" to be blind realize that we must be alert and work to overcome such problems. Otherwise, we'll get caught up in a web of defeat.

Some of us have joined together to overcome obstacles and even strive to reach the pinnacle of being "number one." The NFB works for all those currently blind and for those who might eventually become blind. We must overcome the continuing negatives, misunderstandings and myths now, to prevent more from developing later. You can help.

Before I tell you how, we'll take a quick glance at our success record. We helped pass laws against discrimination in public buildings, in jobs or regarding access to areas where guide dogs are prohibited. We also helped pass a law which allows people without a driver's license under 21 years old to get a special identification card for cashing checks.

We host educational seminars about jobs, parenting blind children, the aging blind, and higher or continuing education. We offer programs and provide speakers, films and other information about specifically built appliances and aids. We can identify valid information sources and discuss personal experiences of overcoming negative circumstances. We strive for excellence and show the positive achievements we can accomplish as blind people. Our greatest contribution as a group is providing information and hope.

But how does this affect you? First, more than 500,000 Americans are blind or visually impaired. Generally, the older one gets, the more likely he or she is to have visual problems. At the same time, when a blind person can't get a job, he or she may become dependent on the American welfare system. We all end up supporting that individual Who provides such assistance? Taxpayers like you!

We need your help. We're striving to overcome the myths, the high unemployment rate, the unfair treatment in areas like insurance. We need your help. It takes financial commitment and that's where you can help out.

We're a non-profit organization run totally by volunteers. We own only one building — our National Center for the Blind headquarters in Baltimore, MD.

One good way to raise new hope right now would be to give us a generous tax-deductible donation. By so doing you're helping strengthen the team to which the Diabetic Division belongs. Americans everywhere will be grateful for your help in our campaign. Please make donations payable to the National Federation of the Blind and send to:

Ed Bryant
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All of your blind brothers and sisters thank you for your time and consideration.

*If you or a friend would like to remember the National Federation of the Blind in your will, you can do so by employing the following language:*

*"I give, devise, and bequeath unto National Federation of the Blind, 1800 Johnson Street, Baltimore, Maryland 21230, a District of Columbia nonprofit corporation, the sum of $_____ (or "_____ percent of my net estate" or "the following stocks and bonds: _____") to be used for its worthy purposes on behalf of blind persons."*

Dear Ed,

Congratulations on the wonderful job done putting together the first NFB Diabetic Newsletter. It certainly will be a valuable source of information for us all.

Although I am one of the nondiabetic members of this organization, I am blind (with some visual acuity), working as a Health Educator. I focus on diabetes education and have worked as a Hemodialysis Nurse in the past. You can see why every aspect of the newsletter was very interesting to me!

I am enclosing a copy of the Staple Templet Technique for measuring insulin. That may be considered worth mentioning in a future edition. As an additional recommendation along with this, I use colored tape to reinforce the templets and find contrasting colors that low acuity individuals can see easily, when it is necessary for mixing insulins and using more than one guide to draw accurately.

Once more, I thank you for putting so much effort into this service.

Feel free to contact me, if there is anything I might be able to help you with.

*Sincerely,*
*— Cecilia Shannon*

*We thank Cecilia for her comments and for providing us with this (see "Modifications on Insulin Techniques" in this issue) and other useful material for our newsletter.*

# Modifications on Insulin Techniques for the Visually Impaired or Blind Diabetic

by Alice Raftary, B.S., M.Ed.

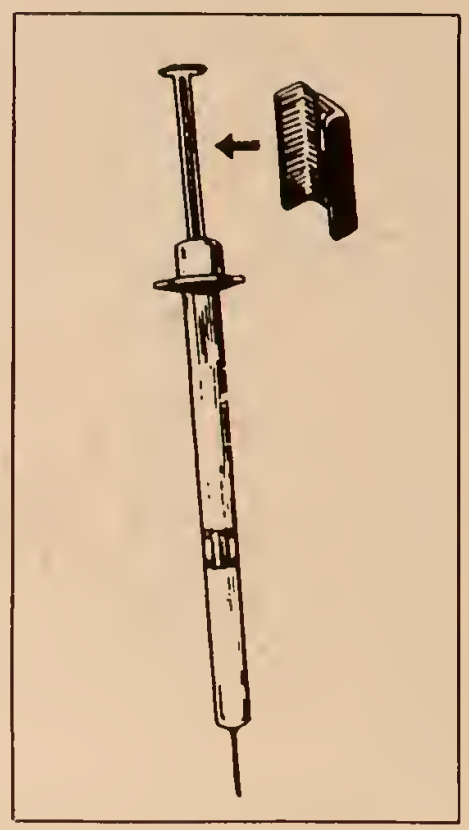
*The following article is printed with permission from Alice Raftary, Supervisor of Teaching at the Greater Detroit Society for the Blind, 16625 Grand River Avenue, Detroit, Michigan 48227.*

*Ms. Raftary requires us to publish the following admonition: The patient should have the procedure monitored by the individual's physician or nurse.*

## MAKING THE TEMPLET

A templet provides a simple, easily handled, accurate measuring device for the insulin dose. One may be simply and economically made of refill staples and a soft adhesive tape (masking, mystic, surgical, etc.).

Directions: Set the dose on the syringe. Break off a length of exposed plunger. Remove a few staples at a time, until the length of staples fits snugly between the syringe barrel. Wrap the length of staples, including one of the angles, with tape to insure permanence and rigidity. Check the accuracy of the templet.



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Note: A new templet must be made if there is any change in prescription or in the make or model of syringe.

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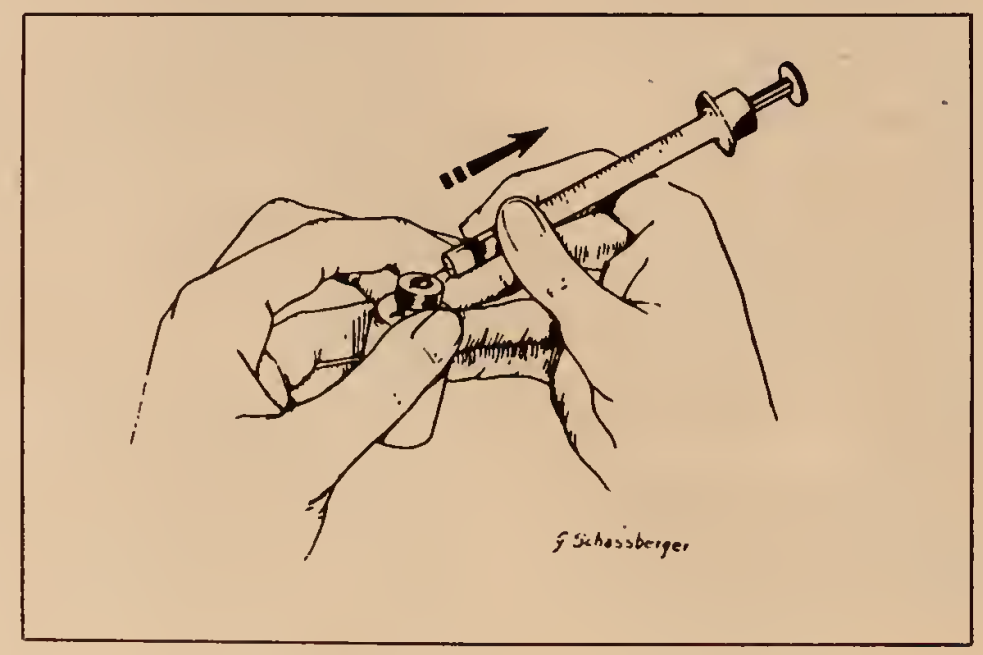
In the dominant hand, hold the syringe near the needle hub as a pencil. With the other hand, hold the insulin vial firmly upright on the table, thumb and forefinger at the neck of the vial.

As the needle is brought to rest across the vial top, the free fingers of the hand holding the syringe will help locate the vial and steady the hand.

Draw the needle across the vial cap. There will be a small "click" as the tip comes off the metal ring onto the rubber. Rotate the syringe to the perpendicular and insert it into the vial. If the needle is not on the rubber, there will be resistance. Don't force it, as the needle will bend. Start over.

## TECHNIQUE FOR DRAWING UP INSULIN

- Assemble all equipment on a small, shallow tray or box.
- Mix insulin by rolling the vial gently between the palms of the hands.
- Cleanse the vial cap with an alcohol swab. Return to tray.
- Uncover the needle. After the needle is uncovered, the syringe does not leave the hands until it is ready for disposal. Draw air into the syringe to the amount of the in-



sulin dose by placing the templet along the shaft of the plunger and seating it snugly. Remove the templet and return it to the tray for easy relocation.

• With the vial resting firmly upright on the table, insert the needle. Expel the air into the vial (Fig. A).

• Slowly invert the vial with syringe attached. Hold it in the vertical position in one hand, leaving the dominant hand free to manipulate the plunger. Keep the equipment in a vertical position until the insulin is fully drawn (Figs. B and C).

• With the dominant hand, pull out the plunger approximately 1/4" farther than necessary to insert the templet. Position the templet along the plunger shaft (Fig. B). Push the plunger up so that the templet is seated. The insulin in the syringe is the dosage prescribed (Fig. C).

FIG. A

FIG. B

FIG. C

### ADDITIONAL PROCEDURES FOR TWO INSULINS IN A SINGLE DOSE

• Make two templets. One templet should be made to measure the units drawn first. The other templet is the length of the combined dose. Be sure the insulins can be differentiated tactually (e.g., a rubber band around one of the vials).

• Draw up air with the longer templet to the combined dose.

• Remove templet and insert needle in vial of insulin to be drawn second.

• Place the small templet along the shaft of the plunger, and expel air into the vial until the small templet is seated.

• Withdraw syringe with templet still in place.

• Insert needle into the vial of insulin to be drawn first.

• Remove templet and expel air.

• Draw up the first part of the dose, following the procedure described in this manual.

• Remove the needle from the vial, keeping the templet in place. Return the vial to the tray.

• Keeping the templet in place, insert the needle into the second vial.

• Invert the vial, and remove the small templet, drawing up a few units.

• Set the longer templet with the end resting on the end of the plunger, and carefully pull out the plunger, steadying the templet with the thumb until the templet drops into place and is seated (Fig. C). Do not expel any insulin back into the second vial.

• Withdraw the syringe from the vial with templet in place. If extra insulin was drawn, discard it by seating the templet.

• Remove the templet and proceed with injection.

### TECHNIQUE FOR INJECTION

• With the free hand, pick up the alcohol swab between the fingers, leaving the thumb and index finger free. Use the swab to cleanse the injection site.

• Keeping the swab between the fingers, pinch up the cleansed area between the index finger and thumb.

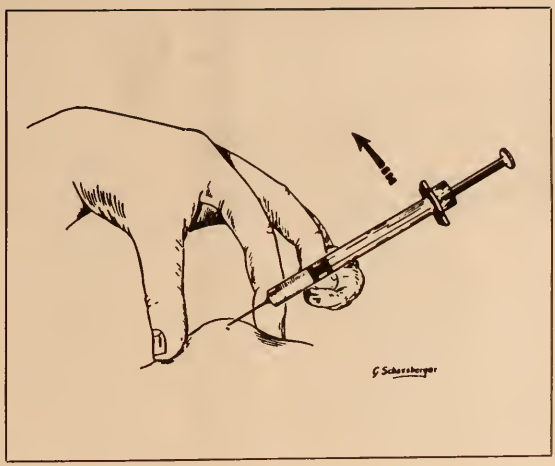
• Place the needle at the injection site. The needle should be at a slight angle, lightly touching the skin. Do not jab. The syringe is then pivoted so that it is nearly perpendicular to the flesh.

• Insert the needle and inject the insulin.

• Bring the alcohol swab to the needle. As the needle is withdrawn, press the site with alcohol swab.

• Cover the needle and dispose of the syringe.

(Continued on next page.)



(Continued from previous page.)

### ANSWERS FOR YOUR QUESTIONS

**Q.** Why use these particular materials for the templet?

**A.** They are readily available, almost without cost, and easy to assemble. Of course, other materials may be used, e.g., plastic or metal tubing.

**Q.** What about sterilizing the templet?

**A.** Not ncessary. It does not come in contact with the insulin or parts of the syringe that contact the insulin.

**Q.** Must new templets be made often?

**A.** A new templet is necessary when: There is a change in the amount or type of Insulin prescribed; there is a change in the manufacture or model of the syringe to be used by the patient; if it becomes raggedy after much use.

**Q.** Must disposable syringes be used?

**A.** Yes. 1) They eliminate the problem of sterilization. It is almost impossible for the blind patient to reassemble a syringe without contaminating it. 2) The inside of a disposable syringe is always smooth and dry. Sometimes bubbles form in a reusable syringe as the insulin is drawn because there is moisture or some chemical build-up in the barrel due to boiling during sterilization. 3) The plunger of the plastic disposable syringe is easier to control than the glass plunger of a reusable syringe.

**Q.** How will the patient know if there are bubbles in his dose?

**A.** He won't. That is why so much care must be taken with the drawing-up technique:

- mixing gently by rolling between the palms to avoid bubbling by agitation.
- injecting air with the vial firmly upright on the table so that one doesn't blow bubbles into the insulin.
- inverting the vial slowly to prevent a bubble from forming in the neck of the vial near the cap.
- holding the vial vertically so that the needle does not extend beyond the insulin level.
- not drawing a dose when the insulin level is less than 1½cc.
- drawing up a little more insulin than the required dose, and expelling the excess to seat the templet.

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Note: It is important for the patient to know that bubbles in his dose would only reduce the amount of insulin administered and not harm him (i.e., would not produce an air embolus).

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**Q.** Why must air be injected?

**A.** Balanced pressure in the vial makes the plunger easier to control during the draw.

**Q.** How will the patient know when the insulin is low in his vial?

**A.** The patient should know how many doses he has in a vial. He will save the last 1½ or 2cc until he can have a sighted person draw them up.

**Q.** How will the patient know if the needle is in a blood vessel?

**A.** He won't. However, as injection sites are in fleshy areas and the needle does not penetrate deeply, only a small capillary would be encountered resulting in a slight hematoma. Insulin entering the blood stream directly in this way would not be in a dangerous amount.

**Q.** What about the brittle diabetic whose insulin dose is frequently adjusted.

**A.** Several templets of different sizes may be made for him.

**Q.** Is some independence possible for the patient who cannot master these techniques?

**A.** Predrawn syringes or additional aids (e.g., needle guides) may be helpful.

Note: if syringes are predrawn, they should be limited to a ten-days' supply, as the insulin tends to crystallize and the plunger will stick.

### A FINAL NOTE

Insulin technique is only one of the personal management and daily living skills necessary for the visually impaired or blind diabetic.

Contact an agency serving the blind for consultation, and for referral of patients for rehabilitative services. — Greater Detroit Society For The Blind, 16625 Grand River, Detroit, Michigan 48227. Phone 313-272-3900.

### EDITOR'S ADDENDUM TO *MODIFICATIONS ON INSULIN TECHNIQUES*

*Question No. 5 says "Not draw a dose if the insulin level is less than 1½cc." One must always be careful. If one holds the insulin vial straight up and down or parallel to the body, it is safe for the vial to have as few as 60 units. The syringe will remain submerged in insulin without the needle protruding into the air.*

*I myself stop using a vial when it contains one cc. or 100 units. The key is holding the vial straight up and down. Remember, there are 10ccs or 1,000 units in each vial.*

*Question No. 10 states that if syringes are predrawn, they should be limited to a 10-day supply of insulin, since insulin tends to crystallize and make the plunger stick.*

*I have conversed with many physicians and health educators who consider a seven- or eight-day supply of predrawn insulin a better method. Several admitted they were uncertain. The 10-day supply might be safe but they were not sure.*

*We also realize that templet staple procedure is not appropriate for everyone. I want to stress that from personal experience, most people don't need a physician or nurse to draw up their insulin or to make a templet staple device for them.*

*Most long-term diabetics can competently explain to any partner how to construct a "templet staple" device. If he or she cannot or if the person making the device is not at least somewhat mechanically inclined, only then should a professional be summoned to help make the device.*

*Once a device has been completed, a sighted person can simply examine it to make sure the insulin dose is correct.*

*Often professional medical personnel charge from $20 to $30 for their services. The diabetic can avoid this fee by letting a friend or relative construct the templet.*

*On the other hand, there are several aids and appliances which the blind person can employ to insure the individual's accuracy in this case. One such device is the Insulgage Syringe Guide, manufactured by Meditec, Inc., based in Englewood, CO. We shared this information with you in our first newsletter, Vol. 1 No. 1, in the "Resource Section."*

*Blind people can use these syringe guides to draw up accurate amounts of mixed insulins. This method is very reliable, but is more expensive than the templet staple technique.*

*I have spoken with numerous professionals. Unfortunately, many don't understand "blindness," or they assume that blindness is "the end of the world." They don't believe we can act independently or think for ourselves. We blind people recognize, however, that by using innovative or alternative techniques, there is little we can't manage to achieve or accomplish for ourselves.*

*A professional rehabilitation agency should train and encourage its staff to involve the agency's blind consumers in all phases of their program.*

*The (blind) consumers should learn several methods of measuring their insulin independently. Unfortunately, many rehab counselors prefer treating blind people like invalids or patients. They end up teaching their blind consumers to function dependently — to rely on others — instead of taking responsibility for themselves.*

*These statements are both optimistic and realistic. People who belong to our organization, the National Federation of the Blind, prove this repeatedly. We prove that blind people can do for ourselves and be graded on our merits, rather than on misconception or myth.*

*While I don't agree totally with Ms. Raftary's article, I do believe she made several valid points.*

*On a final note, I — your editor — am totally blind. I have drawn my own insulin accurately by myself for several years without any trouble.*

**Blueberry Muffins (1 dozen)**
Carol Anderson, Randolph, N.J.

1⅓ cups All purpose flour
1 cup Oats (quick or old fashioned, uncooked)
¼ cup Brown sugar substitute
1 Tbsp. Baking powder
½ tsp. Salt
½ tsp. Cinnamon
1 cup Skim milk
1 egg beaten
3 Tbsp. Vegetable oil
1 cup Fresh or frozen blueberries

Heat oven to 425°F. Spray 12 medium muffin cups with vegetable oil cooking spray or line with paper baking cups. Combine dry ingredients — add milk, egg and oil; stir just until dry ingrdients are moistened. Fold in blueberries — fill muffin cups 2/3 full. Bake 25 to 30 minutes or until light golden brown.

124 Calories. Diabetic Exchanges: 1 bread, 1 fat, 1/2 fruit.

**Chef Veg. Salad With Tuna or Egg**
Ed Bryant, Columbia, MO.

1 Small to medium tomato
1 Heaping cup cauliflower
1 Quart free vegetables: lettuce, radishes, cucumbers, celery, any combination
1 6½-oz. Can water pack tuna (1 oz. equals one meat exchange)
Note: 1 Medium tomato equals one veg. exchange

Dice vegetables and mix together. Flake tuna, and combine with vegetables. (If egg substitute, dice and combine.) Top with Zero Salad dressing.

Note: six-cup salad equals two servings, three cups per serving. Any meat or vegetable may be substituted as long as it is an equal exchange.

145 Calories per serving. Diabetic Exchanges: Three Meats, one Vegetable.

If six eggs are used instead of tuna, each salad would serve two people.

Three eggs per serving — 240 Calories. Diabetic Exchanges: Three Meats, one Vegetable.

Depending on individual diet, a different number of eggs and/or tuna ozs. should be used for meat exchanges.

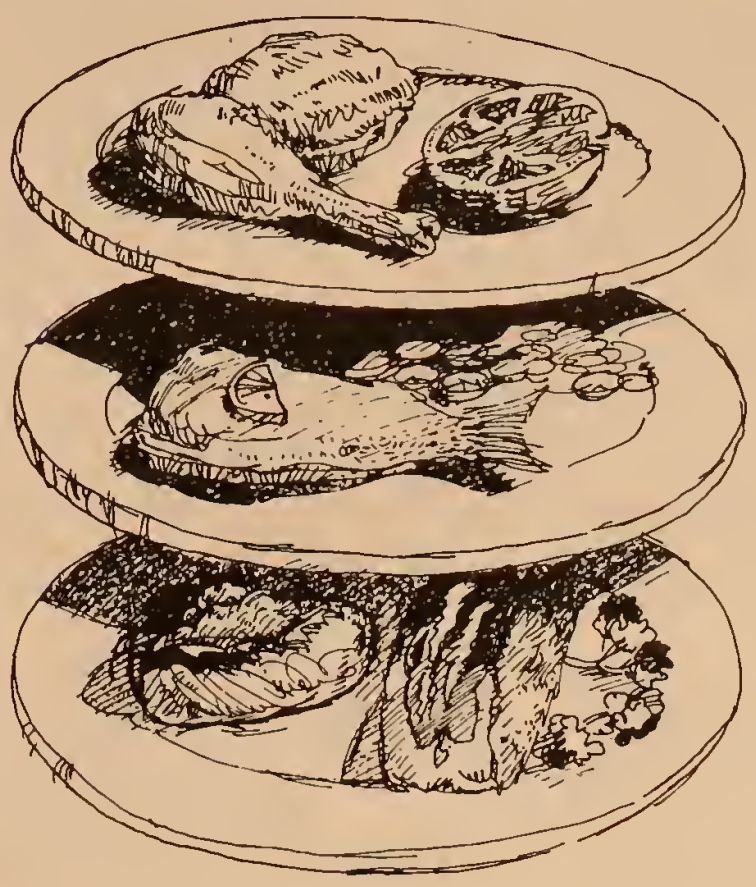
**Zero Salad Dressing**
Frances Allen, Columbia, MO

½ cup Tomato juice
2 Tbsp. Lemon juice or vinegar
1 Tbsp. Onion finely chopped
Pinch Salt (optional)
1 tsp. Pepper

Chopped parsley, green pepper, horseradish, or mustard may be added if desired. Combine ingredients in a jar with tightly fitted lid and shake well before using.

20 Calories equals 1/2 cup. 1/2 cup counts as one Veg. exchange.

Note: if used sparingly — i.e. two Tbsps. at a time, it's a free exchange.



## Meat Exchange List

by Diabetes Treatment and Education Center
(of Columbia, Missouri)

Meat exchanges are a good source of protein needed by the body. One serving of medium fat meat contains about 7 grams of protein, 5 grams of fat and 75 calories. Meats should be prepared without fat or flour except in the amount allowed in your meal plan. All weights are for cooked meats without bone or fat. Meats should be lean and trimmed well of fat before cooking. Weigh all meat after cooking.

| Lean-Medium Fat Meats | (Measure - Grams) | |
|---|---|---|
| Meat and poultry (beef, lamb, pork, chicken, turkey, veal, tongue, liver, organ meats) | 1 oz. | 30 |
| Fish: Any fresh or frozen | 1 oz. | 30 |
| Canned salmon, tuna, mackerel, shrimp, and lobster | ¼ cup | 30 |
| Clams, oysters, scallops, shrimp | 1½ oz. | 45 |
| Sardines, drained, 3" long | 3 | 40 |
| Cottage cheese, 4% | ¼ cup | 45 |
| Cottage cheese, 1% | ½ cup | 90 |
| Cheese: Mozzarella, Ricotta, Low-fat, Farmer's cheese food (spreadable), Neufchatel, Provolone, Velveeta | 1 oz. | 30 |
| Grated Parmesan | 3 Tbsp. | 15 |
| Egg | 1 | 55 |
| Peanut butter | 2 tsp. | 12 |
| Peanuts | 1 Tbsp. | 12 |

| High-Fat Meats | (Measure - Grams) | |
|---|---|---|
| For each exchange of high-fat meat omit one fat exchange: | | |
| Cheese: Cheddar types, Brick, American, Muenster, Monterey Jack, Swiss | 1 oz. | 30 |
| Cold cuts (4½"x1/8") | 1 slice | 40 |
| Hot dog, frankfurter | 1 small | 45 |
| Sausage | 1 oz. | 30 |
| Capon, duck, goose | 1 oz. | 30 |

| One Meat and One Bread Serving | (Measure - Grams) | |
|---|---|---|
| Dry beans, cooked | 2/3 cup | 130 |

Note: One-fourth pound of raw lean meat is the same as three ounces (90 grams) cooked meat. 1/4 cup of cooked diced meat is the same as one ounce (30 grams) meat.

# My Pancreas Transplant — The Impossible Dream

(Continued from page 2.)

"All I can tell you at this time is that the donor is a 14-year-old boy from Fargo, N.D."

I looked at my parents and my brother and said, "I don't think you're going to believe this." My mother gasped and said, "It's the Muir boy, isn't it?" Indeed it was. My brother went to call my other brothers and sisters to tell them what was happening: that he (Jim) would not donate his pancreas, but there was another one available. He called my sister Barbara, who we lovingly call our own little Edith Bunker because of things she sometimes says. When he told Barbara of his decision, she answered him, "Jim, you're just like Abraham, God told Abraham to take his son Isaac and climb that mountain to build an altar to sacrifice him (his son).

"Abraham went up the mountain. Now, I can't help believing that Abraham was human enough to question — why must I sacrifice my only son? But God had commanded him to do this, so he complied. He placed Isaac on top of the altar and was about ready to sacrifice him when God ordered him to stop: 'Abraham, you've done enough. I'm providing you with a substitute for Isaac. And that substitute is the ram caught in the bushes.' " She continued, "Jim, you're like Abraham, God pushed you up that mountain. He took you all the way to the last minute and said, Jim, You've done enough, I've provided a substitute for you. That substitute is a 14-year-old boy who's been killed in a car accident." (Now there's more to the story that I didn't learn for several more days.)

Jim stayed by me for three days following the operation to be sure things were all right. When he felt comfortable with my progress, Dad put him on the plane at Minneapolis, headed for Aberdeen, N.D. Before he boarded, Jim noticed that he had swollen feet. "You know, Dad," he said, "I must have been standing too long, because my feet are a little swollen." By the time Jim got off the plane at Aberdeen, the whole side of his face was swollen shut. He'd had a root canal done the previous month and it had suddenly become infected. Dr. Sutherland assured me that had we used Jim's pancreas for the operation, not only would it have failed once inside me, but I might have died from the infection.

No one can convince me that God is dead. This incident proved once again that God is alive and well and working for me here. God put his arms around me and said, "I'm going to take care of this guy," and that's just what he did.

The life of that young accident victim in Fargo, N.D. was not wasted. Some of you may have watched a program on CBS the other night, called "A Gift of Life." That program showed how people can live on, when others die. It's called "The Organ Donor Plan."

Too few people can discuss death. It's too unpleasant to talk about. The same with donating organs — that's too unpleasant for most people to discuss. Yet it's something very important for most of us to speak of in our homes among families. It's only too possible that some unexpected tragedy will happen to you or a member of your family someday. And maybe you'll have the courage — like the Muir family — to say you're going to donate so others might live. This came home to me only too clearly about a week before I left the hospital. We had a little class that all transplant patients were required to attend to make sure we knew how to take our medicines and to discuss problems before they arose. The woman seated beside me said her husband was alive because that Muir boy had donated his liver. Across the room sat a woman whose husband was alive because that boy had given his heart. Somewhere in the same room were two other unidentified people who lived because that boy had donated his kidneys. And my life was hopefully changed forever, because he had donated his pancreas. Five people in the room were still alive — with changed lives — because one little boy had been sacrificed. I can't help thinking that in this Easter week, talking about sacrifices, and giving up something so others might live, allows a parallel to be drawn.

There are three reasons I want this operation to succeed and my pancreas to work. Today is my 60th day and things are proceeding very well — maybe even better than the doctors expected. The first reason I want it to work is just selfish — for my own life. The second reason is to provide hope for the thousands and millions of diabetics worldwide who will benefit from the research, from my case and from similar operations. Third, I want it to succeed in honor of that little boy who's no longer there for his parents and family, but who lives on in five other people.

If I could live for 1,000 years, I could never express enough to all those who, for 27 years, stood beside me and sacrificed so I might be where I am today. There aren't enough "thank-you"s to be able to say that. My sister Barbara popped up again with something about a year ago. She sent me a special greeting card with the following message written on the outside. It read, "Thank you from the bottom of my pancreas." On the inside it said, "That's almost as deep as my heart — only deeper."

One night after all had worked out, I was lying in bed. I was thinking about the 27 years of hell I lived as a diabetic. I thought, if I could choose a song title to best describe my fight, which one would I choose? I considered "That Long and Winding Road" by the Beatles, but then I came up with something better. It's from "The Man of La Mancha." The song is titled "The Impossible Dream." I selected that one because that's what diabetes and the cure for diabetes seem to be all about. For so many years they've been "an impossible dream, an unreachable star." I stole words from that song and paraphrased them. I'll try to recite them for you this morning. Here are the words that best describe my personal fight with diabetes. My fight with diabetes was:

To dream this impossible dream,
To fight this unbeatable foe,
To try though I often grew weary,
and to go where the brave
would not go,
Yes, to right this unrightable
wrong, though the way got off
and so far,
To reach, though my arms often
got weary, to touch that
unreachable star,
Yes, this was my quest, to follow
that star, no matter how
hopeless — no matter how far,
To be willing to fight without
question or pause,
To be willing to march into hell for
the heavenly cause.
Now the world may be better
for this,
That one man — though he's
covered with scars, through
faith, through family and
friends, and a small dash
of courage,
Has reached that unreachable
star!

Thank you — and God bless you!

# I Lost My Pancreas

(Continued from page 3.)

5) What are the side effects of the immunosuppressant drugs? There are side effects. They may cause hair loss as prednisone did after my kidney transplant; or the drugs cause hair growth, as cyclosporin did after my pancreas transplant. One will probably find some fluid retention — the fat cheek or "Gary Coleman syndrome" as I call it. This is another side effect in taking immunosuppressant drugs. There are other side effects, too. These are spelled out by the people in the transplant office, before the surgery. But believe me, the side effects are minimal compared to *all* the benefits one gets from the operation.

6) One final question that comes to mind is how much will it cost, and does my insurance policy cover that? All insurance policies are different. Some insurance companies will cover it, others will not. My particular insurance policy, an education trust from Wisconsin, is an excellent insurance policy, but it won't cover pancreas transplants because they're experimental. There are others like Blue Cross, which cover it in certain states, but won't in others. So it's best to contact your insurance agent, and check to see what your coverage is. An estimated cost for a pancreas transplant is somewhere between $30,000-$40,000. My operation, including the Rue-N-Y (previous operation) ran somewhere in the neighborhood of $35,000. The question arises: is it really worth it? I had lots of people who helped me raise lots of money. I had enough money to pay for it once. I think there's going to be enough money now to cover most of it a second time. No one likes to have surgery, but when I sat down 18 days after the operation and saw a piece of sour cream raisin pie I could only dream about for 27 years, a piece of pie promised to me by my aunt, that was like a dream come true.

I had been told at one time, "This disease is something you'll have for the rest of your life. There's no cure and nothing to be done for you." That's what *all* the doctors had told me. But there sat that piece of sour cream raisin pie. I knew then, my life had really changed. I'm looking forward to having this operation again. I can't wait for the day. It isn't the sweets; it isn't not having to take shots. The thing that it is, is my "freedom." I'm excited about being independent. With my pancreas, I didn't worry about damages caused by my disease. I felt better; I led a better life.

I mentioned that the University of Minnesota is the hospital that I really trust. I'd recommend anyone wanting further information on this to contact the University of Minnesota directly. Their toll free number is 1-800-328-5465. When you call ask for "Marci." She's the one handling most of the pancreas transplants, and will be the one you should speak with to learn about all the procedures. There are many of them involved in getting set up for a pancreas transplant.

# What You Always Wanted to Know But Didn't Know Where to Ask

(Resource List)

We have not yet tested all these products but are simply advising of their availability.

The National Federation of the Blind (NFB) has more than 50,000 members. It is the largest organized group of blind people in the world. NFB has accumulated lots of information on all subjects relating to blindness. You are cordially invited to contact the National Federation of the Blind with any and all questions that you might have. We are located at 1800 Johnson St., Baltimore, MD 21230. Phone: 301-659-9314.

*JOB Opportunities for the Blind (JOB)* 800-638-7518

JOB is jointly sponsored by the U.S. Department of Labor and the National Federation of the Blind. This is an excellent program and NFB has placed more than 500 qualified blind people in the work force. About 70% of the nation's blind and visually impaired people remain unemployed. The majority of those working currently are underemployed. If you are a blind person and have a vocational goal or have any questions concerning the program, please telephone JOB.

## HOTLINE NUMBERS

Following are hotline numbers so you can obtain free medical information and keep up-to-date on the latest research:

1. Blindness and Physically Handicapped Available Programs. The National Library Service for the Blind (part of the Library of Congress). Phone: 800-424-8567 or in Washington, D.C., 202-287-5100.
2. The American Diabetes Association (ADA), 800-232-3472 or in Virginia, 703-549-1500.
3. Juvenile Diabetes Foundation. 800-223-1138 or in New York, 212-889-7575.
4. **Heart Disease:** Heartline. Sponsored by the Association of Heart Patients. 800-241-6993.
5. **Kidney Disease:** The American Kidney Fund. 800-638-8299. In Washington, D.C., 301-986-1444. In Maryland 800-492-8361.
6. **Surgery:** Second Opinion Hotline. Sponsored by the U.S. Government Department of Health and Human Services. 800-638-6833. In Maryland, 800-492-6603.
7. **Drugs:** Drug Interaction, Drug Side Effects. Food and Drug Administration (FDA). Center for Drugs and Biologics, Office of Consumer and Professional Affairs, Rockville, Md., 301-443-1016.

## BRAILLE MATERIALS

*The Diabetic at Work and Play* (Braille). B.R. Bashell, Springfield, IL; Charles C. Thomas; 1971. 195p.

This four-volume braille edition contains information on oral drugs, diabetic camps, and research among other topics. Price: $26.00. Source: Iowa Commission for the Blind; Fourth and Keosqqua Way; Des Moines, IA 50309. (515) 283-2601.

Thermoform Braille materials (hand-copied) cost nine cents per page. There is a $.75 charge for each volume for binding and labeling.

*The Art of Cooking for the Diabetic.* Contemporary Books, Inc., 12 volumes, 862 pages.

*Eating Right for Less from Consumer Reports.* Two volumes, 42 pages.

Order from: The Braille Institute of America, 741 North Vermont Ave., Los Angeles, CA 90029; Phone number: (213) 663-1111.

## PRINT MATERIAL

*Physical Education and Recreation for the Visually Handicapped.* C.B. Buell, Washington, D.C.; American Alliance for Health, Physical Education, Recreation, and Dance; 1973. 67p.

This paperback book provides information about visual impairments, practical suggestions for activities in physical education and recreation programs (with minimum modifications for various age groups), and an extensive bibliography. It includes a section on activities for the visually handicapped child. Price: $3.75. Source: American Alliance for Health, Physical Education, Recreation, and Dance, 1201 16th St., N.W., Washington, D.C. 20036. (202) 833-5541.

*FORECAST Magazine,* Published by the American Diabetes Association (ADA).

The blind or visually impaired person can receive FORECAST on disk record. You should contact your cooperating library for the blind and physically handicapped. If you need help, you can telephone the toll free number of The National Library Service for the Blind: 1-800-424-8567.

1. *Diabetic's Total Health Book,* by June Biermann and Barbara Toohey. This book is designed to help the diabetic deal with stress. It includes relaxation techniques, autogenics and visualization techniques. Cost: $3.95. Order number: 9005. Order from: Sugarfree, Inc. (address below).

2. *Feeling Good,* by David Burns, M.D. Alter your moods, dispose of the "black holes" of anger, depression, lethargy, etc., with this book. Cost: $4.50 (California residents add sales tax). Order number: 9014. Order from Sugarfree Center, Inc. (address below).

3. *Special Diet Foreign Phrase Book.* When travelling, this book will assist in explaining dietary needs in Spanish, French, German or Italian. This foreign language phrase book covers all diets: soft and low residue, bland, ulcer, low cholesterol and fat, low sodium and diabetic. It has large print and includes medical emergency phrases. Cost: $10.95 (California residents add appropriate sales tax). Order number: 9062.

Order from: Sugarfree Center, Inc., P.O. Box 114, Van Nuys, CA 91408.

## FORM FOR SUBSCRIPTION, DONATION OR MEMBERSHIP

Membership in the Diabetic Division of the National Federation of the Blind (NFB) costs $2.00 yearly, tax deductible. However, production costs for Voice of the Diabetic run about $6.00 per year for each subscription. Members are invited and non-members are requested to cover this cost. If you wish to join the NFB Diabetic Division, subscribe to Voice of the Diabetic, and/or make a donation, please mark the appropriate boxes and fill in the blanks below.

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Carol Anderson, 23 Lake Shore Drive South, Randolph, NJ 07869
Please make all checks payable to the NATIONAL FEDERATION OF THE BLIND.

# Tidbits and Humor

### Newsletter Cassette Tape

If you are a member of the Diabetic Division of NFB and are blind or visually impaired, you can enjoy our newsletter on cassette tape at no additional charge. The cassettes, duplicating, cassette holders and handling are donated to us by the South Dakota State Library for the Blind and Physically Handicapped. This saves us a substantial amount of money and it is essential that we abide by the library's one requirement. *The tapes must be returned to the library within 30 days after they are received.*

If you are a division member and want a newsletter cassette to keep, you can send one dollar to your editor and you will be sent your own tape.

The S.D. State Library keeps each newsletter tape for a one-year period and if you are on their mailing list they will send you past newsletter cassettes for your enjoyment. If you are on our divisional cassette tape mailing list and do not receive your tape you should contact Brian Lopez, at the S.D. State Library, 800 N. Illinois, Pierre, S.D. 57501. (605) 773-3131.

If you have not returned the past cassette tapes that the library has sent you, you will not be sent another.

If you are desirous of receiving our newsletter on cassette *and are not yet on the mailing list*, you must contact Ed Bryant. To repeat, if you *are* already on the cassette mailing list, you should contact the S.D. State Library with any newsletter/cassette tape problems.

**Q:** Do you know why the turtle crossed the road?
**A.** To get to the Shell station!

### Did You Know?

Your editor is always happy to receive credit and recognition, but as he is ultimately responsible for production of this newsletter, you should know that he is responsible for any foul-ups and goofs, etc. Let the editor hear from you concerning what you like or what you do not like about our newsletter. What great suggestions do you have that might help our publication? Do you have tidbit items, such as announcements you would like to have made? Send your editor questions for Dr. James and recipes for our food corner. Provide us with short jokes and/or anecdotes for our tidbit section. Most importantly, provide us with stories or articles about yourself. We are an organization of the blind and always want to share experiences people have had regarding vision loss, blindness and/or diabetes.

**Q:** Do you know why most lighthouse keepers like to raise hens?
**A:** Apparently they like eggs with their beacon!

### It's A Fact

I was recently told that a physician living on the East Coast publicly stated that he did not feel nationwide publications should print stories regarding major chronic diabetes complications. Your editor does not agree with this philosophy, as facts are facts and people should be enlightened as to the complications many diabetics undergo. No one likes to talk about death or losing a leg, or having a major heart attack or going blind, but these things happen every day. We will provide a place where our members' voices can be heard, and experiences can be shared with our brothers and sisters. We have many members who have undergone no major diabetic complications and perhaps our newsletter will give readers more incentive to take good care of their disease. There are no guarantees in this world, but there is very strong circumstantial evidence that the diabetic who controls his/her glucose and blood pressure levels is far less likely to have chronic complications. This will perhaps serve as "food for thought."

**Q:** When is a door not a door?
**A:** When it's ajar!

### Tidbit

Ken Carstens, Chairperson of our Amputations and Prevention Committee, suggests we use the following in our tidbits and humor section.

My wife and I are avid gardeners. I love to get on my hands and knees and plant and weed. I find it easier to remove my prosthetic leg when doing so. Imagine the surprise on strangers' faces when they see a leg sticking out of a row, but no body!

**Editor's Note:** Each of us should have a good positive attitude about our disease, even if we have undergone chronic diabetes complications. Humor accentuates a positive note and is upbeat.